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ABSTRACT

This paper is a description and an evaluation of the Families First program in Sydney, Australia. The Families First program was set up to provide innovative family-centered early intervention services to families with young children with disabilities from birth to school age living within the South-Western Metropolitan Health Region. The program takes a family-centered approach. It identifies family needs, locates the informal and formal supports and resources to meet these needs, and helps families identify their strengths and capabilities to make use of the available resources needed to strengthen the family unit. In this context, children are encouraged to pursue their own learning in playful interaction with others. The Families First program includes activities such as home visits, meetings for the support group "Monday Group" and intervention program "Stepping Stones," social activities, support for liaison with professionals and community groups, and visiting speakers. An evaluative parent satisfaction questionnaire was compiled to ascertain information about parental perceptions of the program. The 10 families whose children no longer require the full range of Families First services were approached and asked to complete the questionnaires. Results from seven completed questionnaires showed that the program has been successful. The Monday Group was the most appreciated aspect of the program. There was a strong utilization of the Stepping Stones program, and parents showed a similarly strong interest in locating information about other resources available in the community. (MOK)

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Families First: Learning from Parents through Evaluation

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The Families First Program was established to support parents and their severely disabled children from birth to three years of age. As the first cohort of parents prepared to leave the program, an evaluation was undertaken with them using a parent satisfaction scale, based on the work of Rosenkoetter, Hains & Fowler (1994) to gather information about three key aspects of their experience. In the first instance, information was needed about the value of different elements of the program. Second, although information was available elsewhere about the impressive developmental gains made by the children, it was important to understand how the parents themselves perceived those gains (McBride, Brotherson, Joanning, Whiddon & Demmitt, 1993). Thus, items on the scale were designed to provide insight into the levels of parent confidence in their children's growth and change as well as their own changing self-view in terms of adaptiveness, most importantly resolution of conflict, risk-taking, and re-negotiation of roles. Thirdly, the authors were interested in ascertaining parents perceptions of the processes involved in the re-negotiation of their roles. The four processes which were identified were the grieving stage, acquisition of knowledge, building of confidence based on the newly acquired knowledge and acceptance. The results of this investigation validated the particular balance of elements in the program.

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The Program

The Families First program was set up to provide an innovative family centred early intervention service to families with young children with disabilities from birth to school age living within the South-Western Metropolitan Health Region. The program takes a family-centred approach, inspired by the work of Dunst, which is directed by three guiding principles. These are, first, to identify family needs; second, to locate the informal and formal supports and resources to meet these needs and third to help families identify their strengths and capabilities to make use of the available resources needed to strengthen the family unit (Dunst, Trivett & Deal, 1988, 1994; Dunst, 1991). Within this general context, the principles of good early childhood practice are utilised. That is, children should be encouraged to pursue their own learning in playful interaction with others. The teacher's role should be to support, facilitate and extend this process rather than direct it. Johnson & McChesney-Johnson (1992) believe that non-directive teaching strategies in conjunction with specialised individual teaching plans are desirable for disabled children. These then are the foundational principles upon which the Families First program has been based.

Aspects of the program

Home Visits: The coordinator of the program, an early childhood teacher with skills in counselling, can be called on by participant families to make home visits when required. Home visits are beneficial for both parties. The family can be helped with particular problems they may be experiencing at the time and the coordinator is able to understand more about the family context - a key aspect for family centred programs. Consequently, a more personal dimension is added to the relationship between the coordinator and the families.

Monday Group: The Monday group addresses the needs of both parents and children in a play setting. Participants meet each Monday at the Macarthur Occasional Care Centre. Children, supervised by staff and parents, engage in planned informal play activities and are directed towards reaching goals outlined in the Individualised Family Support Plan (IFSP). For example, a child with cerebral palsy may need to be given postural support in order to reach and explore with confidence. Parents are given the opportunity to withdraw for a "sharing" session with other parents over morning tea. The purpose of this is to enable parents to talk amongst themselves, in this way creating a support network. A staff member, trained in counselling skills, is present to facilitate the discussion. Non-disabled siblings are actively encouraged to attend the groups with the objective of fostering interaction between non-disabled and disabled children.

Stepping Stones: The key objective for this program is to prepare children with disabilities and their families for the transition from early intervention to an integrated preschool placement. Stepping Stones is co-located on-site with a mainstream early childhood program. During the morning session, time

is spent with the children in the mainstream setting. The program is designed to meet the children's individual needs within a play-based, developmentally appropriate curriculum where materials and settings are similar to those in the preschool. Staff consist of an early childhood special education teacher and two assistants. Teaching strategies aim to foster the children's ability to explore and utilise materials and participate in activities that promote social interaction.

Social Activities: The social activities are organised primarily to enhance the relationships between families and staff of the program. Such activities include weekend barbeques and household gatherings. Another advantage of these events is that fathers are usually available to attend and can therefore receive similar support and knowledge from the program.

Support for Liaison with other activities: For families with disabled children, it is important to identify community based programs and resources able to be adapted to accommodate the specific needs of the disabled children and their families. Staff of the program attempt to develop links with other professionals and community groups involved in service delivery to families of children with disabilities within this region. For example, a local physiotherapist and speech & language pathologist visit regularly to conduct assessments and therapy during the Monday group and at Stepping Stones.

Visiting speakers: Specialists from the broader community, may be invited to the Monday group to speak on issues that may be of relevance to the parents. For example, recently the Department of Education's Early Learning Consultant spoke about transition procedures from early intervention to mainstream education.

The present research was undertaken to assess parents' perceptions of the Families First program. There were three objectives guiding the research. First, the authors sought to find out what parents perceived as the most beneficial aspects of the program. Second, it was important to find out how the parents perceived the changes in their child's development, as well as their own changing self-view in terms of adaptiveness, in particular resolution of conflict, risk-taking, and re-negotiation of role. For the third objective, the authors were particularly interested in the parents' perceptions of the processes involved in role re-negotiation. The following study attempts to provide insights to these objectives.

Method

An evaluative parent satisfaction questionnaire, based on work by Rosenkoetter, Hains & Fowler (1994), was compiled to ascertain information about parental perceptions of the program. The ten families whose children no longer required the full range of Families First services were approached and asked to complete the questionnaires. From these, seven fully completed questionnaires were returned and these responses constituted the data pool.

The questionnaire consisted of both open and close ended questions. The close ended questions were of primary importance for the present analysis because they provided insights into parents' perceptions of their child's development. They were constructed so that for a given statement, for example, "I used to think that having a child with a disability destroyed family life," parents could respond anywhere on a five point scale, i.e, strongly disagree -disagree - not sure - agree - strongly agree. Following initial analysis of the responses, the five categories were collapsed to three , disagree, not sure and agree and the following information is supplied on the basis of this more contracted scale.

Parents had been involved in the program for varying lengths of time. Four respondents had been involved for at least three years, one for two and a half years, one for ten months and the other for nine months.

Evaluation of the Program

The primary aim of the study was to investigate the relative usefulness of different aspects of the program. Initially, respondents were asked to tick the activities of Families First which they had experienced. The results are presented below in tabular format:

Monday Group	100%
Information from Visiting Speakers	100%
Home Visits	86%
Support for liaison with other Services	86%
Stepping Stones	71%
Social Activities	71%
Telephone Contact with Staff	71%
All of the Above	43%

More importantly, parents were asked to tick the aspects of the program they found most useful for themselves and their family. Again, the results are displayed in the table below:

Monday Group	100%
Information from Visiting Speakers	71%
Home Visits	43%
Support for liaison with other Services	71%
Stepping Stones	71%
Social Activities	29%
Telephone Contact with Staff	29%

Obviously, the Monday Group was easily the most appreciated aspect of the program. This is perhaps unsurprising since other aspects which are listed can be fulfilled during attendance at the Monday group. For instance, as part of the Monday group, information about other support services is available, parents have contact with staff and so additional phone contact is perhaps

unnecessary and the morning "sharing" session where parents can socialise with other parents may act as a substitute for the organised social activities.

There was a strong utilisation of the Stepping Stones program within this group. Parents showed a similarly strong interest in locating information about other resources available in the community. This interest could reflect the fact that the parents surveyed were those moving into a later stage of their child's development and were in need of transitional support and knowledge of forthcoming support programs appropriate for their children.

When parents were asked which aspect proved least useful, only three offered suggestions, the others noted 'not applicable' as if implying that all aspects of the program were useful in some way. Out of the three respondents, two noted that telephone contact with staff was least useful and one noted that home visits were not as useful. Again, the former may be explained by sufficient contact being made with staff during the Monday group.

Parent Perceptions

The most important objective of the research was to encourage parents to think about how involvement in the program had affected them. The authors were most interested overall in parents' perceptions of their own adaptiveness. Adaptiveness refers to parents' abilities to accept the birth of the disabled child and integrate the added physical and emotional responsibility into a satisfied and functional lifestyle. Within this context, items which identified resolution of conflict, risk-taking and re-negotiation of roles were of particular interest.

Ideally, to study the process of adaptation, interviews and questionnaires should have been administered at the beginning, in the middle and at the completion of the program. This pilot study presents only material collected at the end of the program year. To compensate, "static" items - the answers to which should not change over time and required no knowledge of the Families First program - were included. Items included "I have always been a person who found it easy to adapt to difficulties" 52% disagreed, 29% were not sure and 29% agreed; and "I have always been resourceful" to which 14.5% disagreed and 85.5% agreed. The array of responses highlight that fundamentally, the parents differ with respect to each other. Generally speaking, though most parents felt resourceful, most had difficulty adapting to their situation.

"Dynamic" items refer to those items to which answers were directly linked to participation in the program. The questionnaire comprised more of these items because an evaluation of the Families First program was the primary aim of conducting the research. The authors hoped that the success of the program would be highlighted with these answers.

Resolution of Conflict: In this respect, the authors were particularly interested in the conflict which results as a direct consequence of bearing a child with a disability. Once a disabled child is born, parents experience a violation of expectation. Conflict may arise from this violation both within the family and within the community. Alienation from established social groups is often an outcome as parents are thrust into a situation where their roles will no longer be what they had expected. Instead of parenting the 'perfect' child , they are forced to spend huge amounts of time with professionals, attending support groups and basically, managing the activities of their disabled child. The authors were interested in the respondents' ideas about resolving the conflict that results from the added pressures of such a child rearing experience.

The majority of parents thought that "most problems can be resolved" (agree 85.5%, disagree 14.5%) and that they knew more about "sharing experiences with others" (71% agreed, 29% not sure). All of them agreed that they now "know that [they] can help others by listening", "feel more confident when talking to professionals" and that "Families First would always give [them] support when [they] needed it". Finally, most of them agreed that they "now believe problems are solved more readily with the support of others" (85.5% agreed, 14.5% not sure).

Risk-Taking This is a more difficult category to describe. The authors were primarily interested about parents' perspectives about the future and their confidence in making decisions which would affect their future. Generally, parents were not risk-takers, rather, most felt that planning was a necessary part of child-rearing. The items, "I think it is important for parents to plan for all children" (71% agreed, 14.5% disagreed and 14.5% not sure). and "Parents of young children with disabilities have more to think about when planning for their children. (71% agreed, 14.5% disagreed and 14.5% not sure) highlighted this. Even still, the parents expressed a willingness "to try anything [which] will help [their] child" (85.5% agreed, 14.5% not sure). The item "The Families First staff should tell me what to do, that's their job" (71% disagreed, 29% not sure) indicated that parents did not see themselves as totally reliant on the support of Families First in rearing their children. They have the confidence and initiative to make decisions on their own.

Re-negotiation of Role refers to parents' evolving perceptions of themselves throughout their disabled child's development. Implicit within the idea of re-negotiation of role is the notion of change. The item which best illustrates the importance of change is "my ideas haven't changed at all". The majority (71%) of parents disagreed with this statement indicating that they had experienced profound change. The third objective of the current project was to analyse the re-negotiation of role, concentrating on the processes which underlie it. The next section addresses this in more detail.

Re-negotiation of Roles

Questions were compiled in an attempt to delineate various processes involved in role re-negotiation. The different stages of parents' role re-

negotiation, once a disabled child was born, were thought to be grief (parents would be subject to the normal process of grieving), the intake of diversified information, building of confidence based on the newly acquired knowledge, followed by acceptance of the situation. The underlying hypothesis was that if these were important parts of the process of parental role re-negotiation, a certain homogeneity of response would be expected for key questionnaire items.

Grief

Grieving is a complex process experienced differently by each individual family member. Families have reported experiencing and re-experiencing aspects of grieving each time they are confronted with making decisions about which they are uncertain. Stress is an important associated factor and it was clear that families have a desire for normalcy. The most important item indicative of this process was "I now recognise that parents of young children need time for grieving". to which 100 % of respondents agreed.

Acquisition of knowledge

The acquisition of knowledge appears to be a crucial stage with the re-negotiation of roles for parents. When parents are expecting a normal child and then have a child with a disability, they are immediately confronted with the need to know more: 'What is the cause of the disability? How will it effect my child's development? Where can we gain support?' Cook, Tessier & Klein (1992) acknowledge that with each change in a child's condition, there are new questions, concerns and challenges. An item which exemplifies the parents' need for knowledge is "I have never needed anyone to tell me what to do with my child". All of the parents disagreed with this statement.

Different types of knowledge:

- Disability

Parents need to obtain information pertaining to the implications, prognosis and management of the disability. All of the respondents noted that they "now [knew] more about disability and its effects". A small proportion of respondents (29%) had once thought that "having a child with a disability destroyed family life" however no longer held that view.

- Utilisation of professionals

A commonly experienced frustration for parents with disabled children is their relationship with professionals. Either they themselves do not feel comfortable interacting with such professionals or they perceive that the professional is not supplying the support that parents feel they need. The questionnaire highlighted that Families First had been beneficial in enhancing the relationships between professionals and parents. That is, 100% of parents felt that they knew "more about getting the help that [they] need[ed]" and felt "more confident when talking to professionals".

- Community Support networks

Community support networks play an important role in supplying information to parents with disabled children. The Families First program is one such example. Almost all the participants "now believe [that] problems are solved more readily with the support of others" (85.5% agreement, 14.5 not sure). All the respondents recognised that they "have learnt from watching Families First staff work with the children" and 85.5% agreed that "Families First has helped me explain my child's needs to other family members and friends" (14.5 disagreed).

Probably the most important thing that parents gain from this process of knowledge acquisition is that their child really is not that much different from other "normal" children. It is often the idea of the unknown which casts a feeling of alienation over the parents and once this is resolved, parents can come to terms with their child's disability. For the items: "I now know that children with disabilities have their ups and downs just like other children" and "Disabled children need the normal experiences of childhood", all of the parents agreed.

Confidence

With the acquisition of knowledge, it seems that confidence gradually builds in parents. Most respondents felt more "willing to explain to other adults why something is important to [them] as a parent of a child with a disability.(85.5% agreed, 14.5% not sure). All parents believed that they had "the right to expect that others will respect [their] wishes as a parent of a child with a disability. The majority felt themselves now to be people "who could adapt to difficult circumstances (71% agreement, 29% not sure) and that they were proud of [their] achievements as parents of a child with a disability (85.5% agreed, 14.5% not sure). Universally, they felt more confident as parents.

Acceptance

Lepler (1978) documents a mother's definition of acceptance with respect to her disabled son.

> 'To me acceptance means finding whatever pleasure I can in caring for Benjamin day to day. It means looking at other children without always wishing he were like them. It means looking at the situation not in terms of what Benjamin can do for me, but what I can do to enhance his potential' (p.33).

Within the context of the questionnaire, parents exhibited their acceptance with 100% agreement on the items: "I am proud of my child's achievement" and "I am looking forward to the next stage of my child's development".

Thus, within the cohort of Families First participants surveyed herein, certain commonalities have been identified in the process of adaptiveness. The processes outlined do not necessarily eventuate in a sequential manner. It

must be remembered that each parent is different and hence, responds to life events in individual ways. Cook, Tessier & Klein (1992) note that 'the sequence and completeness of each phase of adjustment may differ with each individual [and] some may never fully accept their child and his or her condition' (p.65).

Limitations of the Study

The present pilot study provided valuable information about the Families First program and parents' perceptions about the processes involved in caring for a child with a disability. There are several methodological issues which warrant attention. Ideally, a study which aims to assess underlying processes involved in the re-negotiation of roles should be conducted longitudinally. This is the only way to effectively tap changes in perception over time. The current study was limited in that it utilised only a retrospective questionnaire to evaluate perceptions. Another major limitation was the size of the sample. It is hoped that this will cease to be a problem in the future as the Families First program expands and more families participate for the full duration of the program. Finally, these results cannot be generalised to fathers for the sample consisted of mothers only.

Conclusion

In summary, these interim results reveal that the Families First program has been successful in its purpose of providing support to the families of disabled children in the South-West region of Sydney. Aspects of the program which promoted group interaction for children and parents as well, including the Monday group and Stepping Stones, were acclaimed as the most useful. Parents benefit from receiving the opportunity to liaise with other parents of disabled children. Whilst certain key processes were identifiable in parents' adaptiveness when caring for a child with a disability, it must be emphasised that parents maintain their individuality throughout the program. One of its driving principles is that each family setting is distinct. Parents and children enter the program as individuals and are treated as such right through the program. The compilation of an Individualised Family Support Plan for each family entering the program attests to this. The present results clearly indicate that continued financial support is essential in order to sustain the varied aspects of the program and its ability to reach out and support families with disabled children.

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